



**New Jersey Department of Health
Governor's Council for Medical Research and Treatment of Autism
Meeting Minutes – May 19, 2014 (ratified)**

Council Members Present

Elizabeth K. Bell, BS, volunteer and independent contractor with Autism Speaks,
Autism Organization Representative

Caroline Eggerding, M.D., Healthcare Organization Representative and Chairperson of the
Governor's Council for Medical Research and Treatment of Autism

Susan P. Evans, Ed.D. Education Program Specialist for Early Intervention Program,
Commissioner of Health Appointee

B. Madeleine Goldfarb, MA, Founder/Director of the Noah's Ark Children's Association,
Autism Organization Representative

Ketan Kansagra, M.D., FAAP, Children's Hospital of New Jersey at Newark Beth Israel Medical
Center, Academic Institution Representative

Absent

Gary Weitzen, BA, Executive Director, Parents of Autistic Children (POAC) Autism Services,
Organization Representative

NJ Department of Health (DOH) Attendees

Martin T. Zanna M.D., MPH
Acting Executive Director
Governor's Council for Medical Research and Treatment of Autism

Linda N. Bocclair, M.Ed., MBA
Executive Assistant
Governor's Council for Medical Research and Treatment of Autism

Mary Ray, Contract Administrator 2
Governor's Council for Medical Research and Treatment of Autism

Commission on Brain Injury Research
Commission on Spinal Cord Research

Daphne Robinson, Ph.D., Consultant
Scientific Planning Consulting

Public Attendees

Audrey Mars, M.D., Hunterdon Medical Center, Regional Autism Center

Gerard Costa, Ph.D., Center for Autism and Early Childhood Mental Health at Montclair State University and Principal Investigator, NJ ACE Coordinating Center

Karen Hood-Kasim MPH, Project Coordinator, NJ ACE Coordinating Center

Kathleen Freeman Ph.D., RNC-NIC

Cecilia Feeley, Rutgers CAIT

Caroline Rodgers

Kathleen Fadden

Gene Tunik

I. Welcome - Council Chairperson, Dr. Caroline Eggerding called the meeting to order at 6:10 PM and welcomed everyone. She noted that this is a voting meeting and, as a result, public member comments is not included on the agenda.

II. Public Meetings Act Announcement- Dr. Eggerding read the Public Meetings Act, followed by roll call.

III. Approval of the September 9, 2013 Council Meeting Minutes

Dr. Eggerding called for a motion to approve the minutes. MOTION by Ms. Goldfarb to approve the minutes was seconded by Ms. Bell. No discussion.

MOTION to approve the minutes was passed with four in favor and one member absent (member arrived later).

IV. NJ ACE Grantees-Progress Report-Dr. Costa

Discussion: Dr. Costa presented a summary of grantees' progress through the third quarter (March 31, 2014). He highlighted the progress of each grantee and noted several challenges

including subject recruitment, IRB approval and the request by one grantee to transfer her grant to another institution.

Conclusion: Addressing issues for transferring the grant in question is in progress and will be considered when all documents are received by the NJ DOH. To address subject recruitment, the Coordinating Center (CC-MSU) staff will continue to work with grantees to discuss and implement strategies for recruitment. NJDOH IRB approval for one grantee is in progress with a decision anticipated within the next month.

V. Vote for Continuation Funding for Program Site grant

Council was requested to vote for approval for continuation funding for year two of Grant # CAUT13APS010, *The Generation and Characterization of Autism iPSCs*, Principal Investigator James H. Millonig, Ph.D.

Dr. Eggerding called for a motion.

MOTION by Dr. Evans to approve the Progress Report for year two continuation funding was seconded by Ms. Bell.

Discussion: Dr. Costa presented an overview of the grantee's Progress Report and commented that the study is being done well. He had recommended to the NJDOH that the grant be presented to Council for continuation funding. Dr. Zanna concurred.

MOTION to approve the Progress Report for grant # CAUT13APS010, *The Generation and Characterization of Autism iPSCs* year two continuation funding was passed with all in favor.

VI. NJ ACE 2014 Grant Applications

Twenty-nine grant applications were submitted for consideration for funding by the Council. Dr. Eggerding asked the Council staff to comment on the process that lead up to tonight's meeting. Dr. Zanna explained that with the increase in number of applications, the diversity of topics and the short time frame there was a significant increase in the workload as compared to previous cycles. He credited Dr. Daphne Robinson for playing a major role in selecting reviewers thus ensuring their areas of expertise were well matched with the topical areas of each application.

As a result of the number and diversity of applications two review panels were needed with one meeting on April 29, 2014 and the second on April 30, 2014. The last step leading up to the Council meeting was to convene the Scientific Advisory Committee (SAC). The SAC made specific recommendations, including considering funding only applications with scores below 5 using the NIH scale of 1-9 with 1 being the best score.

Dr. Eggerding referred to the Conflict of Interest declaration and asked members to complete the forms and return them to Mary Ray. Members were asked to leave the room when specific grants that they have listed on the forms are discussed to avoid any conflict of interest.

Voting:

CAUT14APL014

Dr. Eggerding called for a motion.

Dr. Evans moved and seconded by Ms. Goldfarb to accept the recommendation to fund CAUT14APL014.

Discussion: A member questioned if the grant should be funded conditionally considering a comment by a reviewer for the need for a genetics counselor.

Conclusion: This was not stated as a condition by the reviewers and typically applications scoring in this range are not awarded conditionally.

MOTION to approve the recommendation to fund CAUT14APL014 was passed with all in favor.

CAUT14APL006

Dr. Eggerding called for a motion.

Ms. Bell moved and seconded by Dr. Evans to accept the recommendation to fund CAUT14APL006.

Discussion: There was a concern with the power of the study if the applicant were unable to obtain the projected number of samples. The need for samples may encourage collaboration for subject recruitment.

Conclusion: Approve without conditions.

MOTION to approve the recommendation to fund CAUT14APL006 was passed with all in favor.

CAUT14APL028

Dr. Eggerding called for a motion.

Dr. Kansagra moved and seconded by Ms. Goldfarb to accept the recommendation to fund CAUT14APL028 with conditions.

Discussion: Council discussed the recommended conditions.

Conclusion: Approve the recommendation to fund with conditions.

MOTION to approve the recommendation to fund CAUT14APL028 with the following conditions was passed with all in favor: (1) develop Aim 2.4 with the help of a medicinal chemist with more expertise with these assays and (2) delete Aim 3.

CAUT14APL031

Dr. Eggerding called for a motion.

Ms. Goldfarb moved and seconded by Ms. Bell to accept the recommendation to fund CAUT14APL031 with one condition.

Discussion: Council discussed the recommended condition.

Conclusion: Approve the recommendation to fund with one condition.

MOTION to approve the recommendation to fund CAUT14APL031 with the following condition was passed with all in favor: consult with an expert in drug discovery to maximize drug discovery potential.

CAUT14APL010

Dr. Eggerding called for a motion.

Dr. Evans moved and seconded by Ms. Goldfarb to accept the recommendation to not approve CAUT14APL010.

Discussion: The major flaw is that the study is not feasible considering the requirement that requires diagnosis at 2 months of age.

Conclusion: Call for the vote.

MOTION to approve the recommendation not to fund CAUT14APL010 was passed with all in favor.

CAUT14APL029

Dr. Eggerding called for a motion.

Ms. Goldfarb moved and seconded by Dr. Kansagra to accept the recommendation to fund CAUT14APL029.

Discussion: Concern that there is a lack of clarity regarding the analysis, measures and validation.

Conclusion: The grantee will need the support of the Coordinating Center to address the concerns.

Dr. Eggerding called for an amended motion.

Ms. Goldfarb moved and seconded by Dr. Evans to accept the recommendation to fund CAUT14APL029 with a condition.

AMENDED MOTION to approve the recommendation to fund CAUT14APL029 with the condition that the grantee confer with the NJACE Coordinating Center to address the concerns listed in the critiques of the application, including analysis, measures and validation was passed with all in favor.

CAUT14APL004

Dr. Eggerding called for a motion.

Ms. Goldfarb moved and seconded by Dr. Evans to accept the recommendation to fund CAUT14APL004.

Discussion: Council addressed the concerns of the reviewers. However, the applicant does have IRB approval and has invested a great deal of effort into preparing the proposal. They do have someone with expertise in ASD on their team.

Conclusion: Vote on motion.

MOTION to approve the recommendation to fund CAUT14APL004 was passed with all in favor.

CAUT14APL005

Dr. Eggerding called for a motion.

Ms. Bell moved and seconded by Ms. Goldfarb to accept the recommendation to not fund CAUT14APL005.

Discussion: The feasibility is questionable, it's a complex algorithm to analyze, exciting technology but very difficult to do. A lot of labs are looking to do this and labs with experience working with programmers and experts in statistics with large groups coming together to try to tease out the data with all the variables. Many concerns including the use of ADOS and issues with the specificity and selectivity of control groups.

Conclusion: Vote on motion.

MOTION to approve the recommendation to not fund CAUT14APL005 was passed with all in favor.

CAUT14APL018

Dr. Eggerding called for a motion.

Ms. Goldfarb moved and seconded by Ms. Bell to approve the recommendation to fund CAUT14APL018, based on a score of less than 5.

Discussion: There was no specific recommendation at this time given that review of this application is pending. Voting for CAUT14APL018 will be held either via conference call or at the June 2, 2014 meeting of Council.

Conclusion: The motion was tabled.

CAUT14APL027

Dr. Eggerding called for a motion.

Dr. Kansagra moved and seconded by Ms. Bell to accept the recommendation not to fund CAUT14APL027. No discussion.

MOTION to approve the recommendation not to fund CAUT14APL027 was passed with four in favor (one member left the room).

CAUT14APL013

Dr. Eggerding called for a motion.

Ms. Bell moved and seconded by Dr. Kansagra to accept the recommendation not to fund CAUT14APL013. No discussion.

MOTION to approve the recommendation not to fund CAUT14APL013 was passed with four in favor (one member left the room).

CAUT14APL15

Dr. Eggerding called for a motion.

Ms. Goldfarb moved and seconded by Ms. Bell to accept the recommendation not to fund CAUT14APL15. No discussion.

MOTION to approve the recommendation not to fund CAUT14APL15 was passed with all in favor.

CAUT14APL030

Dr. Eggerding called for a motion.

Dr. Kansagra moved and seconded by Ms. Goldfarb to accept the recommendation not to fund CAUT14APL030. No discussion.

MOTION to approve the recommendation not to fund CAUT14APL030 was passed with all in favor.

CAUT14APL012

Dr. Eggerding called for a motion.

Ms. Bell moved and seconded by Dr. Kansagra to accept the recommendation not to fund CAUT14APL012. No discussion.

MOTION to approve the recommendation not to fund CAUT14APL012 was passed with all in favor.

CAUT14APL023

Dr. Eggerding called for a motion.

Dr. Kansagra moved and seconded by Ms. Bell to accept the recommendation not to fund CAUT14APL023. No discussion.

MOTION to approve the recommendation not to fund CAUT14APL023 was passed with all in favor.

CAUT14APL037

Dr. Eggerding called for a motion.

Ms. Bell moved and seconded by Ms. Goldfarb to accept the recommendation not to fund CAUT14APL037. No discussion.

MOTION to approve the recommendation not to fund CAUT14APL037 was passed with all in favor.

CAUT14APL016

Dr. Eggerding called for a motion.

Dr. Evans moved and seconded by Ms. Bell to accept the recommendation not to fund CAUT14APL016. No discussion.

MOTION to approve the recommendation not to fund CAUT14APL016 was passed with all in favor.

CAUT14APL020

Dr. Eggerding called for a motion.

Ms. Bell moved and seconded by Dr. Kansagra to accept the recommendation not to fund CAUT14APL020. No discussion.

MOTION to approve the recommendation not to fund CAUT14APL020 was passed with all in favor.

CAUT14APL036

Dr. Eggerding called for a motion.

Ms. Goldfarb moved and seconded by Dr. Kansagra to accept the recommendation not to fund CAUT14APL036. No discussion.

MOTION to approve the recommendation not to fund CAUT14APL036 was passed with all in favor.

CAUT14APL001

Dr. Eggerding called for a motion.

Ms. Bell moved and seconded by Dr. Kansagra to accept the recommendation not to fund CAUT14APL001. No discussion.

MOTION to approve the recommendation not to fund CAUT14APL001 was passed with all in favor.

CAUT14APL019

Dr. Eggerding called for a motion.

Dr. Evans moved and seconded by Dr. Kansagra to accept the recommendation not to fund CAUT14APL019. No discussion.

MOTION to approve the recommendation not to fund CAUT14APL019 was passed with all in favor.

CAUT14APL017

Dr. Eggerding called for a motion.

Dr. Kansagra moved and seconded by Ms. Goldfarb to accept the recommendation not to fund CAUT14APL017. No discussion.

MOTION to approve the recommendation not to fund CAUT14APL017 was passed with all in favor.

CAUT14APL021

Dr. Eggerding called for a motion.

Dr. Evans moved and seconded by Ms. Bell to accept the recommendation not to fund CAUT14APL021. No discussion.

MOTION to approve the recommendation not to fund CAUT14APL021 was passed with all in favor.

CAUT14APL009

Dr. Eggerding called for a motion.

Dr. Kansagra moved and seconded by Ms. Goldfarb to accept the recommendation not to fund CAUT14APL009. No discussion.

MOTION to approve the recommendation not to fund CAUT14APL009 was passed with all in favor.

CAUT14APL035

Dr. Eggerding called for a motion.

Ms. Bell moved and seconded by Dr. Kansagra to accept the recommendation not to fund CAUT14APL035. No discussion.

MOTION to approve the recommendation not to fund CAUT14APL035 was passed with all in favor.

CAUT14APL034

Dr. Eggerding called for a motion.

Ms. Goldfarb moved and seconded by Ms. Bell to accept the recommendation not to fund CAUT14APL034. No discussion.

MOTION to approve the recommendation not to fund CAUT14APL034 was passed with all in favor.

CAUT14APL008

Dr. Eggerding called for a motion.

Dr. Kansagra moved and seconded by Dr. Evans to accept the recommendation not to fund CAUT14APL008. No discussion.

MOTION to approve the recommendation not to fund CAUT14APL008 was passed with all in favor.

CAUT14APL033

Dr. Eggerding called for a motion.

Ms. Goldfarb moved and seconded by Ms. Bell to accept the recommendation not to fund CAUT14APL033. No discussion.

MOTION to approve the recommendation not to fund CAUT14APL033 was passed with all in favor.

CAUT14APL022

Dr. Eggerding called for a motion.

Ms. Bell moved and seconded by Ms. Goldfarb to accept the recommendation not to fund CAUT14APL022. No discussion.

MOTION to approve the recommendation not to fund CAUT14APL022 was passed with all in favor.

VII. Election of the Council Chair

Dr. Zanna called for nominations. Dr. Evans nominated Dr. Eggerding. There were no additional nominations. Ballots were distributed; members voted and unanimously elected Dr. Eggerding as Chairperson for 2014. Dr. Zanna congratulated Dr. Eggerding as she continues to chair the Council. Dr. Eggerding thanked the members.

IV. Report of the Acting Executive Director, Martin T. Zanna, M.D. MPH

National Recognition

Dr. Zanna noted that the IACC (**Interagency Autism Coordinating Committee**) Strategic Plan Update released on April 30, 2014 included the State of NJ in the section on NDAR (National Database for Autism Research) as a participant along with CDC, the Department of Defense, the Simons Foundation, and Autism Speaks. As a result of this recognition, NDAR accepts data

directly from the Council's grantees and enables the grantees to access data from researchers nationwide.

Council Membership

Recommendations for appointments and reappointments to the Council were sent by the Commissioner's office to the Governor's Appointment office in February 2104 and are currently being reviewed by the Governor's staff.

Report on NJ ACE Grantees

Final reports for the 2010 basic and clinical research grants will be presented to Council at the September 8, 2014 Council meeting. Most of the grantees were awarded no cost extensions through 2013 with one through June 2015.

NJ ACE Coordinating Center

Dr. Zanna thanked Dr. Costa for his very informative report of the grantees' progress. Dr. Zanna is pleased to hear that grantees are progressing as planned and that the Coordinating Center is supporting them in addressing challenges such as subject recruitment while providing training on ADOS and consulting on research design and other areas of need. Dr. Costa introduced Karen Hood-Kasim as the new project coordinator. She previously served a research associate for the Coordinating Center. Dr. Eileen McKeating has been selected as the new research associate and will begin on July 1, 2014. Dr. McKeating comes from the University of Pittsburgh. She has over 10 years of evaluation research involving multi-site, statewide projects and she has both programmatic and clinical experience in autism and early intervention.

Funding for FY 15 and FY16

Dr. Zanna requested that the Council discuss funding initiatives for FY 15 and FY 16 at the June 2 meeting to provide more time for the next RFA cycle. The reason being with the increase and diversity of topics seen in the last two RFA cycles it is becoming an increasing challenge to both develop the RFA and to process applications within a relatively short time frame given the multiple steps involved. Starting the process early will help to further ensure Council receives all the required grant related review information as early as possible to inform their funding decisions. This will, in turn, assure the most highly qualified applications receive Council's recommendation for funding.

April 9, 2014 *Translational Research in Autism* Conference

Dr. Zanna noted that attendees' comments will be tabulated; however, in general the comments were positive. Ms. Goldfarb, who initiated the idea of conferences for researchers starting with the 2012 conference, was pleased to see so much interest in the 2014 conference. Ms. Bell provided an overview of the agenda for those who were not able to attend. She was particularly

impressed with the topics selected for group discussions and the sharing of ideas from different perspectives. Dr. Michael Lewis from Rutgers was credited with the idea of group discussions. He identified topics and recruited group leaders for the 2014 conference as he had for the 2012 conference. Dr. Eggerding commented that it was a remarkable collection of creative thinkers in attendance. All who attended agreed that the venue was outstanding (the Conference Center at Montclair State University).

V. Report of Revenues and Expenditures

Discussion: A member asked about the line of appropriated funds. Mary Ray explained that the Council received \$500,000, annually for the last three years, in appropriated funds from the state (not the moving violation revenue) budget to cover office expenses. The Council covers \$500,000 for the Autism Registry. A member expressed concern over the funds (\$250,000) given to Autism New Jersey for the autism hotline and the possibility that additional funds could be awarded through legislative action.

Conclusion: In response to a member's question regarding membership on the Council it was noted that Autism New Jersey is not represented on the Council. Four seats on the Council are designated for autism organizations, not specific organizations. Any qualified organization may apply.

VI. Adjournment

Dr. Eggerding asked for a motion to adjourn.

MOTION to adjourn by Ms. Goldfarb and seconded by Dr. Evans was approved with all in favor.

The meeting was adjourned at 8:45PM.